The British Institute of Human Rights
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The Joint Committee on Human Rights Inquiry into the human rights implications of the UK Government's Covid-19 response:

Evidence from advocacy, community and voluntary sector groups

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1. Executive summary

BIHR welcomes this opportunity to provide evidence to the JCHR as part of its inquiry into the human rights implications of the Government's response to Covid-19. Our policy responses are directly informed by people's real-life experiences of the issues, drawn from our work to support people to benefit from their human rights in their daily experiences. Our key findings are summarised below:

- Over 65% of advocates and campaigners who responded to our call for evidence told us that it has been more necessary to use human rights to challenge poor practice during Covid-19.

- Over 45% of advocates and campaigners who responded to our call for evidence told us that they thought that the specific characteristics or needs of the people they support (for example, but not limited to), disabilities, mental health or capacity issues, race or ethnicity, age, gender were not considered when decisions were made. Over 27% believed that specific characteristics were considered but in a negative way.

- 50% of advocates and campaigners who responded to our call for evidence told us that during Covid-19 there was no clarity about which law was being used to allow for a change of care and support.

- Over 43% of advocates and campaigners who responded to our call for evidence told us that where changes to care and support were made during Covid-19, people were not told by the service changing their care where they could raise an issue.

2. Background

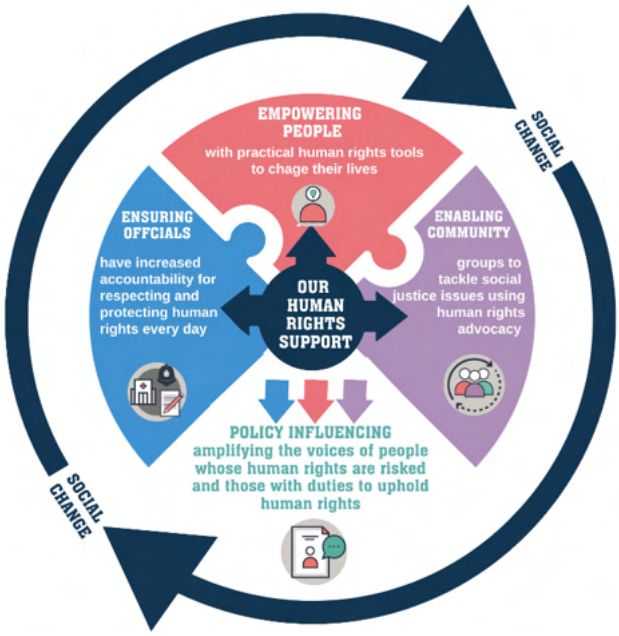
The initial Coronavirus Act was passed very quickly, and UK government has issued both law (Regulations) and guidance at speed, often with conflicting or confusing public messaging. There are some welcome references in the Coronavirus Act which make it clear that decisions to change care and support should not be incompatible with human rights. However, this was not accompanied by measures to enable people to understand what these human rights are and ensuring that frontline workers know how to make rights respecting decisions. Thus there are two elements to accountability for the responses to Covid-19: a) central Government's response through law, policy, guidance and resourcing; and b) the implementation of these responses at local level, and therefore people's everyday experiences of risks to their human rights.

3. Methodology

The British Institute of Human Rights is a charity working in communities across the UK to enable positive change through human rights.

We work with three main groups across the UK:

1) People accessing (or trying to) access services, their family members and people who care about them.
2) Formal advocates (e.g. IMCA, IMHA, etc.), self-advocates, and other community, campaigning, and advocacy groups.
3) People with legal duties to respect and protect rights. Including those working in public services and those working in private, charitable, or voluntary bodies delivering public services.



a) BIHR's evidence submission

Since March 2020 our work has specifically focused on the impact of Coronavirus law and policy on people and its implementation through local decision-making. Across the UK, we have worked with over 400 people accessing public services including their families and those who care about them and over 950 people working in health and care services including advocates and campaigners.

The evidence gathered through our work informs our main concerns and suggestions for the steps that need to be taken to ensure that measures taken by the Government to address the Covid-19 pandemic are human rights compliant.

We have prepared an evidence submission for each of the groups we work with, so that the Committee members have access to the direct experiences of all three groups when considering the Government's response. This submission focuses on the experiences of advocates and campaigners. For the purposes of this JCHR report, the data will be shown as UK wide. We will be submitting nation specific data to devolved inquiries where appropriate.

Important demographics to note when considering the evidence contained in this report:

- **Where in the UK**
  - 100% of those who responded to our call for evidence work in England.

- **Type of community group**
  - 78.26% identified as formal advocates (e.g. Independent Mental Capacity/Health Advocate)
  - 13% identified as self-advocates
  - 4.35% identified as non-statutory community advocacy.

- **Assisting people with care and support needs:**
  - Over 86% support older people with physical disabilities and/or health care needs
  - Over 78% support adults with learning disabilities and/or Autism
  - 78% support older people with mental health needs

- Over 4% support children with physical disabilities and/or health care needs
- Over 4% support children with learning disabilities and/or Autism.

b) PANEL approach

As a human rights organisation, we ourselves use a human rights approach. We have used the PANEL human rights framework endorsed by the United Nations in our evidence gathering and as the structure of our submission.

We take each principle in turn, sharing people's experiences and in doing so answer the questions the Committee is seeking views on through the lens of human rights:

What steps need to be taken to ensure that measures taken by the Government to address the COVID-19 pandemic are human rights compliant?

What will the impact of specific measures taken by Government to address the COVID-19 pandemic be on human rights in the UK?

Which groups will be disproportionately affected by measures taken by the Government to address the COVID-19 pandemic?

Click on the headings below to read the evidence for each human rights principle.

Participation
Accountability
Non-discrimination
Empowerment
Legality

4. Evidence on the human rights impacts for people with care and support needs

a) Participation

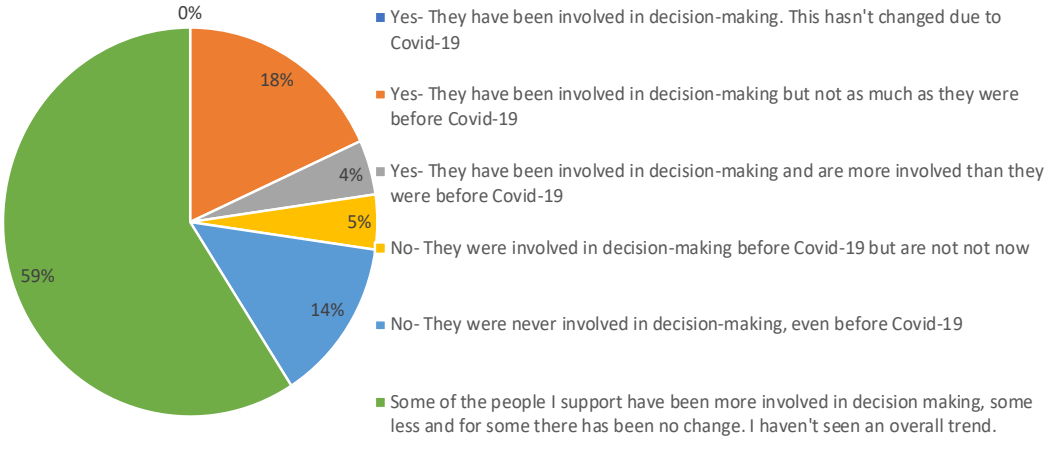
In order for the measures taken by the Government to address the Covid-19 pandemic to be human rights compliant: **People should be involved in decisions that affect their rights.** Autonomy is covered under Article 8 of the European Convention, brought into UK law in the Human Rights Act 1998 ("HRA"), which also includes the legal duty on public authorities to respect and protect this right in their everyday functions.

In people's daily lives, this means that changes to care and support should be discussed with the individual, their family or other chosen person. Where the person has been assessed as lacking capacity to make specific decisions about care (or changes), the safeguards under the relevant capacity legislation must be met. These safeguards include, encouraging and enabling participation, considering past wishes and feelings, consulting anyone named by the person and much more.

What did advocates and campaigners tell us about participation during Covid-19?

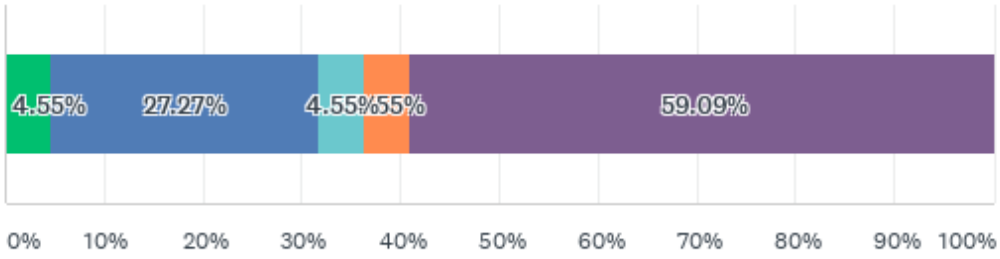
Advocates and community groups reported concerns about involvement in decision-making.

a.1 We asked, "Since the start of Covid-19 have the people you support been involved in decision-making affecting their care and support?"



"So many things have been put on hold e.g. introduction of new care packages, managed housing moves that there has been less opportunity for clients to be involved in decision making. Although where action has been able to be taken clients have been able to be involved. Some clients have had more problems dealing with communicating without face to face support though."

a.2 We asked, "Since the start of Covid-19, when decisions have been made about the people you support's care and support were they told why this decision was made and for how long it would last?"



- Yes- They are informed in the same way as they were before Covid-19
- Yes- They are informed but this has got worse since Covid-19
- Yes- They are informed, and this has got better since Covid-19
- No- They have not been informed and were not informed before Covid-19
- No- They have not been informed, this has only happened since Covid-19
- Some of the people I support have been better informed, some less and for some there has been no change/ I haven't seen an overall trend.

a.3 Further elaboration from advocates and campaigners

"There was a top down LA approach to safeguarding from virus at first- very much too little too late. Clients where there were longstanding disputes, BI [best interests] decisions made to move them into places they didn't want were made opportunistically and unilaterally. Took a while for them to start working with advocacy again... by then virus was spreading in some of the homes."

"They have been involved if I have been able to speak with them. I am not sure that professionals involved in hospital discharge have had full regard for the person's wishes"

"Practice is really varied, but generally there is a decrease in involvement..."

"People have been told that OTs [occupational therapists], CPNs [community psychiatric nurses] etc would not be able to support face to face but they have not been told how long this situation would last... nobody seems to know how long the situation will last."

BIHR's recommendations for ensuring participation:

- The Government, both centrally and locally must make it entirely clear that all legal duties under the Human Rights Act remain in place regardless of Emergency

Coronavirus legislation. This includes the right to autonomy (having a say over your care) under Article 8 (HRA).

- It must be made clear that where a person's participation in decisions about their care and support is restricted, this restriction must follow the 3-stage test of lawful, legitimate, and crucially proportionate (the least restrictive option possible).

- Clarity must be provided around the use of Emergency Powers, it must be made clear that where any changes are made to a person's care and support, the person and their chosen family/friends (those who will be impacted) must be supported to be involved in decision making. Easements must be applied compatibly with human rights law.

- All public officials must be supported to recognise and respond to a situation in which a person's legally protected human rights are at risk. This is necessary during Covid-19 and beyond.

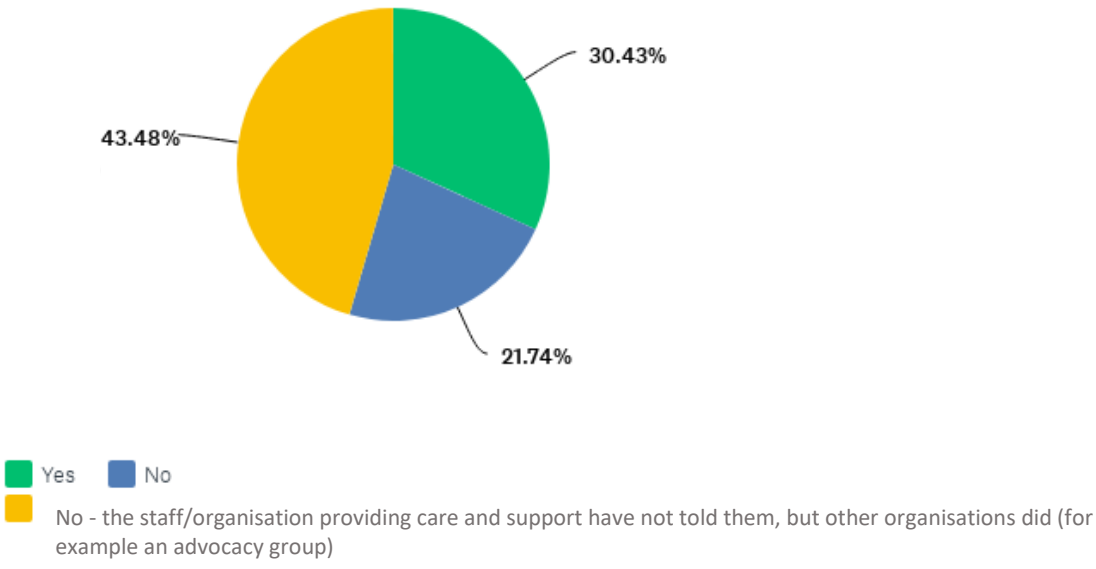
b) Accountability

In order for the measures taken by the Government to address the Covid-19 pandemic to be human rights compliant: **There should be monitoring of how people's rights are being affected, as well as remedies when things go wrong.**

The section 6 HRA duty places a legal duty on public officials (and those delivering a function of a public nature) to respect, protect and fulfil human rights. This duty is about every decision frontline staff make, the policies and protocols put in place by managers, and the strategic decisions of leadership. This does not change under Coronavirus law and policy.

What did advocates tell us about accountability during Covid-19?

b.1 We asked, "When a decision has been made about the people you support's care or support, did staff or the organisation providing that care and support tell them about how they could challenge this decision or raise an issue about it?"



b.2 Further elaboration from advocates and campaigners

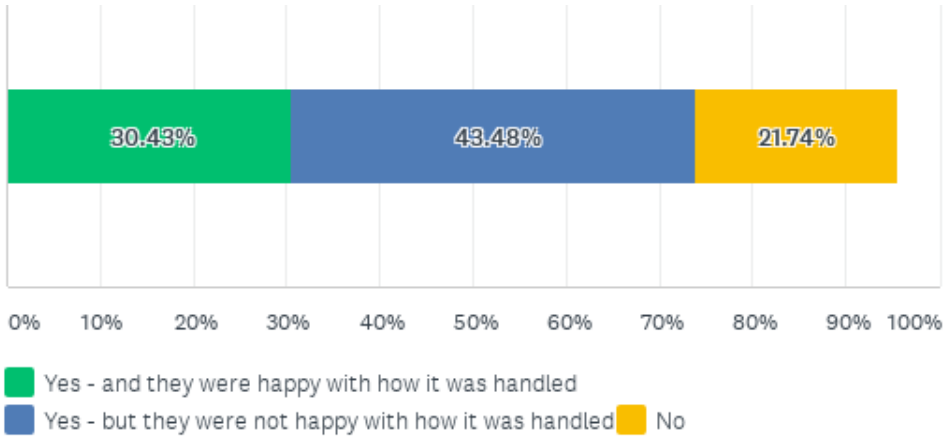
"Where possible we are advising people as usual about right to challenge, but the advocacy is more complex and not as effective because of the way decisions are made within inadequate BI decision processes... Feels bleak as advocacy very ineffective"

"Challenges around covid restrictions not really effective as top down LA and care provider decision making."

"In my experience people who support are not great at providing information to challenge a decision. This falls generally to a BIA [Best Interests Assessor] or Advocate"

"This applies to one particular case when the care agency were failing in their support to the extent it was neglect. Organisation repeatedly said they were addressing this but evidence showed otherwise. Social Care were prepared to keep giving them chances but Statutory Advocate had to step in to challenge and have the care provider changed."

b.3 We asked, "When the people you support have raised an issue or challenged a decision was this reviewed or addressed by the staff or organisations providing the care and support (or another organisation they complained to)?"

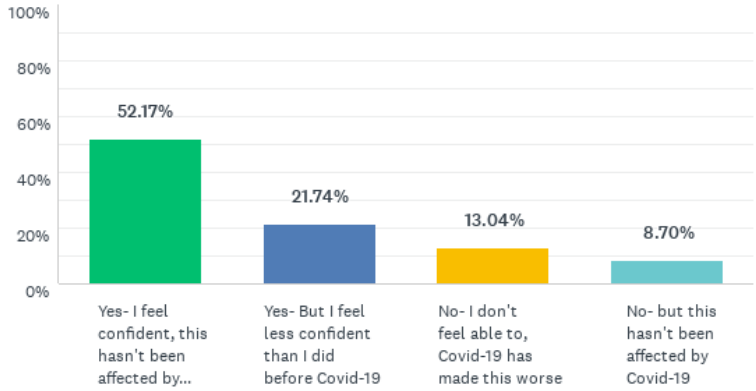


b.4 Further elaboration from advocates and campaigners

"Yes I feel confident to challenge, but at the moment I am reliant on information from staff and I don't always think that is an accurate reflection."

"With staff/individual providers, yes (although sometimes they raise complaints which the charity are not very supportive to advocates about)."

b.5 We asked, "Do you feel able to raise a concern or challenge with staff about the people you support human rights when decisions are being made about their care and support?"



BIHR's recommendations for ensuring accountability:

- There must be open and accessible processes for people, their families and those who care about or support them (such as advocates) to raise issues with care and support during Covid-19.
- Where there have been changes to complaints processes as a result of Covid-19 these must be the least restrictive option available to the public service (i.e. there cannot be a blanket suspension of complaints procedures, this is not a proportionate response). Advocates must be informed of new processes (i.e. a move online) to enable them to ensure the people they support have their voices heard.
- There must be clear avenues and processes for advocates to raise issues they are facing when trying to uphold human rights during Covid-19.
- Information about the Emergency Powers being used at local level should be monitored locally and centrally via a robust procedure. People working in advocacy and campaigning must be consulted about their experiences. This enables informed decisions to be made about the continued availability of the Powers. In doing this, the Government can identify trends and concerns, including human rights flash points during the pandemic, as well as positive practice which others can learn from.

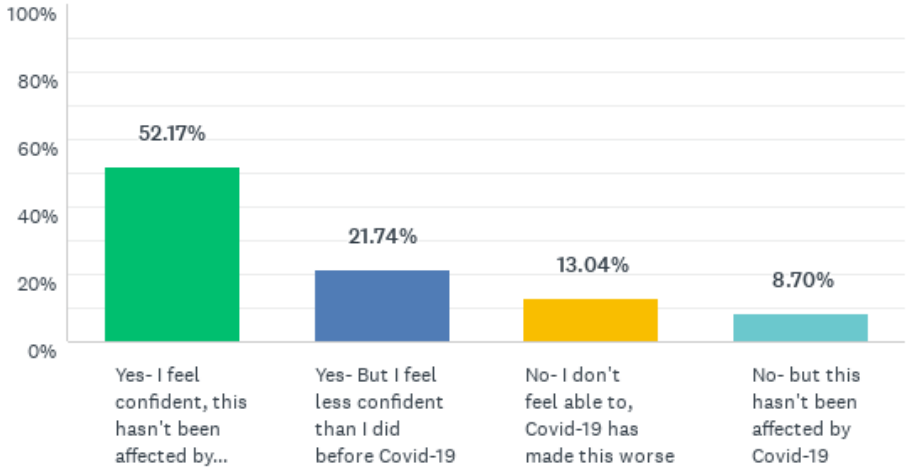
c) Non-discrimination

In order for the measures taken by the Government to address the Covid-19 pandemic to be human rights compliant: **Both direct and indirect discrimination must be prohibited, prevented and eliminated. People who face the biggest barriers to realising their rights should be prioritised.**

Article 14 in the Human Rights Act sets out that the enjoyment of rights and freedoms must be secured without discrimination on any grounds, including but not limited to sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status. Importantly, and differently to the Equality Act, this encompasses discrimination beyond the nine protected characteristics, and recognises discrimination based on combined or multiple factors, such as having Autism and living in a residential unit or being an older person and living in a care home.

What did advocates and campaigners tell us about discrimination during Covid-19?

c.1 We asked, "Do you think those making decisions about care and support during Covid-19 considered the specific characteristics or needs of the people you support? This could include (but is not limited to) considering any disabilities, mental health or capacity issues, race or ethnicity, age, gender or other characteristics or needs."



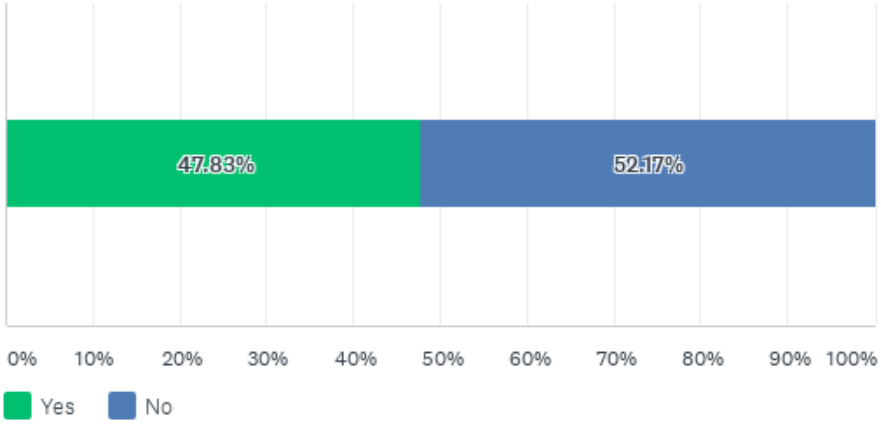
c.2 We asked, "Do you believe any of the above issues, that the people you support have experienced, were also about treating them worse than other people because of a particular identity or characteristic they have?"

"Age and physical health/ disability"

"English as second language. No native speaking care staff."

"Because of age (older people); dementia; perceived poor quality of life due to disability; learning disability"

c.3 What did advocates and campaigners tell us about which groups are affected by measures?



c.4 Further elaboration from advocates and campaigners

"...discharged to the nearest available bed without considering suitability"

"This is not for all people I support, not those on the ward, but some community clients."

"MCA weaponised to make emergency and paternalistic decisions. Especially at start of pandemic, there was a lot of pressure on advocacy team to rubber stamp decisions."

BIHR's evidence gathering has highlighted concerns of direct and indirect discrimination impacting the following people: from our wider work we know that this list is not exhaustive and will be publishing more expansive data:

- Older people
- People with dementia
- People with English as a second language
- People with learning disabilities and/or Autism
- People with physical disabilities
- People with mental health issues
- People with mental capacity issues

BIHR's recommendations for ensuring non-discrimination:

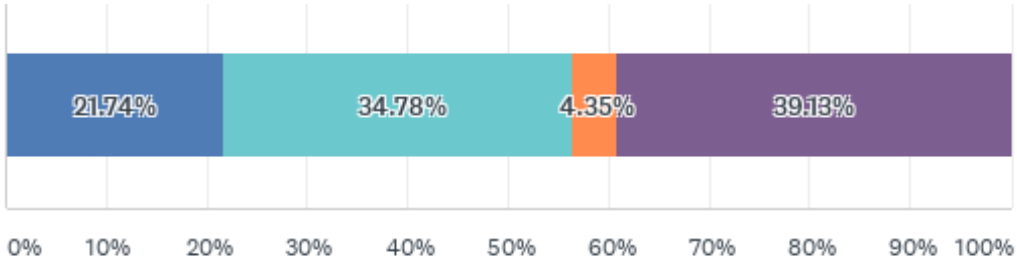
- The Government must ensure that all public officials are fully trained, resourced, and supported to practically implement their legal duties under both the Human Rights Act (1998) and the Equality Act (2010).
- The Government must make it entirely clear that these non-discrimination legal duties have not changed as a result of Covid-19, and to ensure that their actions responding to Covid-19 are not discriminatory in themselves.
- Where the Government has knowledge that discrimination has occurred (i.e. through this evidence call) this should be independently investigated, using human rights as the central framework and remedies put in place.

d) Empowerment

In order for the measures taken by the Government to address the Covid-19 pandemic to be human rights compliant: **Everyone should understand their rights and be fully supported to take part in developing policy and practices which affect their lives.**

What did advocates and campaigners tell us about empowerment?

d.1 We asked, "Since the start of Covid-19, when a decision is being made about a person you support's care and support have decision-makers told them about their human rights in this situation?"



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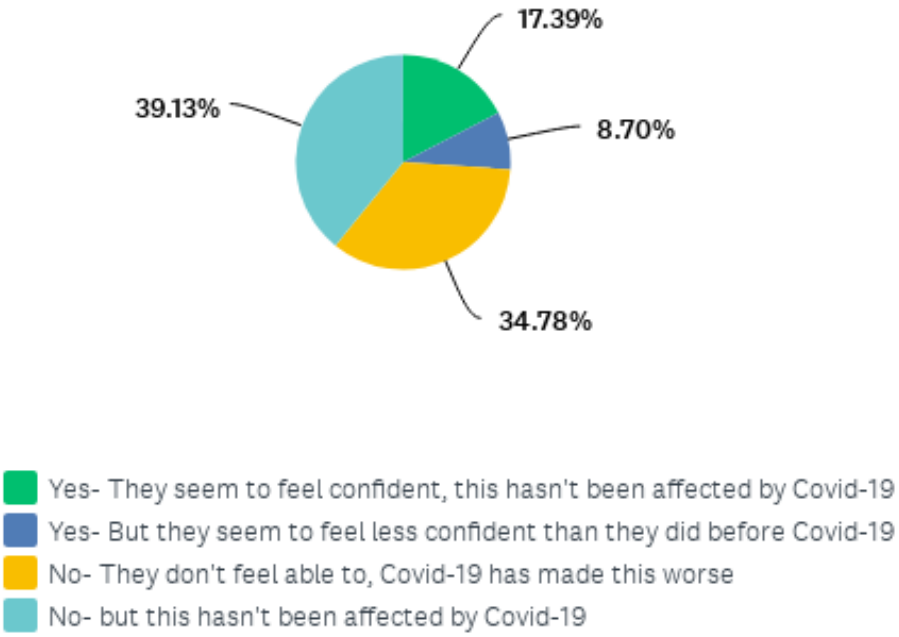
d.2 We asked, "Do the people you support feel able to raise a concern or challenge with staff about their human rights when decisions are being made about their care and support?"



BIHR recommendations for ensuring empowerment:

- The Government communications about Covid-19 (and beyond) should be centred in human rights. Thus far there has been very little evidence of this, even though the main responses to the pandemic focused on rights-restricting measures.
- All public officials must be trained, resourced and supported to embed human rights law in every interaction and to involve people in those discussions and decisions.
- People must be provided with easy to access, accessible information that enables them to understand their rights during Covid-19.
- The Government must make it clear that everyone in the UK has human rights protected in law, that these are relevant to their everyday interactions with public authorities, with clarity on which rights can be restricted (the process for doing this lawfully, legitimately and proportionately) and which can never be restricted even during a pandemic for example, the right not to be tortured or treated in an inhumane of degrading way (Article 3, HRA).

e) Legality

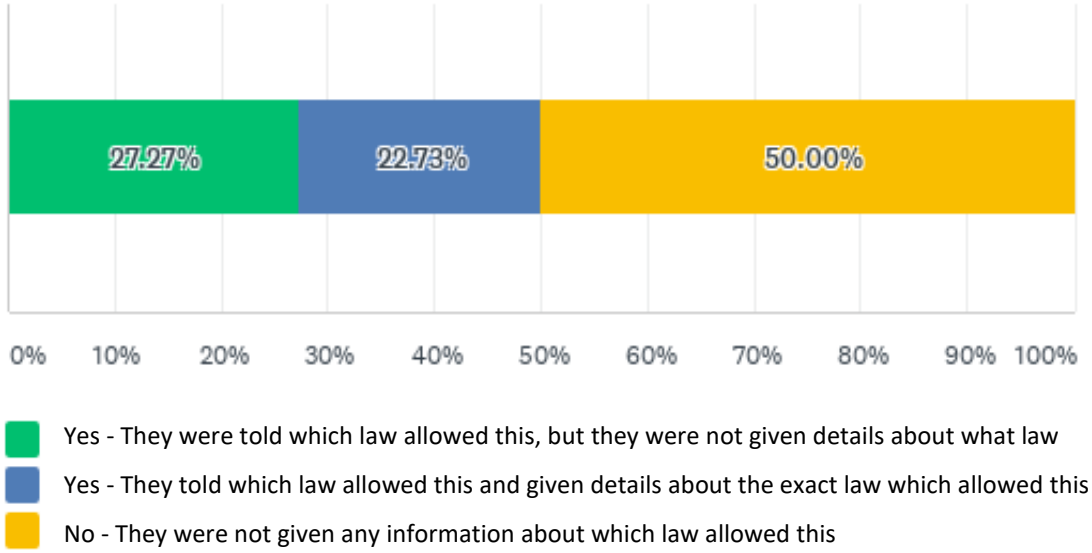
In order for the measures taken by the Government to address the Covid-19 pandemic to be human rights compliant**: Approaches should be grounded in the legal rights that are set out in domestic and international laws.**

Domestically we have 16 rights under the HRA. Some of these rights can be restricted in certain very specific circumstances for example, to protect the individual or the wider public

from harm). Where this has been the case during Covid-19, any restrictions have to be applied lawfully, for a legitimate aim and in a way that is proportionate to the risk. Other rights within the HRA, such as the right to life can never be lawfully interfered with by the state, that remains the case during Covid-19.

What did advocates and campaigners tell us about legality?

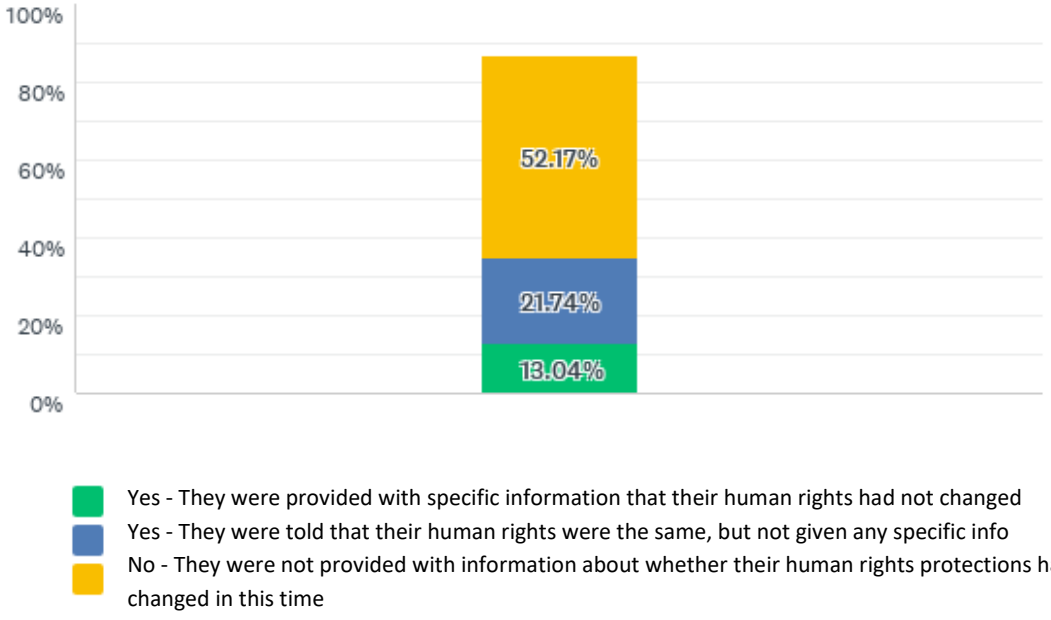
e.1 We asked, "Since the start of Covid-19, if a decision is made about the care and support of a person you support, were they told which law allowed this change?"



e.2 Further elaboration from advocates and campaigners

"Generally our clients wouldn't ask about or understand specific laws but we do talk to them about the decisions and how to challenge..."

e.2 We asked, "Since the start of Covid-19, if a decision has been made about the people you support's care and support were they made aware that their legal rights under the Human Rights Act have NOT changed in this time?"



Key human rights issues identified by advocates and campaigners during Covid-19

Advocates and campaigners who responded to our evidence call identified experiencing or being aware of the following rights issues during Covid-19:

Right to life (Article 2 HRA)

29.17%

of advocates and campaigners told us they have experienced

A failure to protect life due to lack of resources, cuts to services or decisions to prioritise other services

70.83%

of advocates and campaigners told us they have experienced

Do Not Resuscitate Orders put in place or pressure to make them without being involved in the decision

41.67%

of advocates and campaigners told us they have experienced

Failure to test for Covid-19 before admission to residential care leading to spread of infection and death

Right not to be tortured or treated in an inhuman or degrading way (Article 3 HRA)

34.78%

of advocates and campaigners told us they have experienced

Someone being moved or detained in an inappropriate place due to a shortage of beds or community support which has a severe impact on mental and/or physical wellbeing

17.39%

of advocates and campaigners told us they have experienced

Someone being subject to abuse, neglect or bullying in a person's living situation with no way to address these during Covid-19

37.50%

of advocates and campaigners told us they have experienced

Removal or change to care or support packages leading to situation where dignity could not be upheld

Right to liberty (Article 5 HRA)

30.43%

of advocates and campaigners told us they have experienced

Someone being detained on mental health or mental capacity grounds without being assessed or without safeguards in place (e.g. being able to know why and challenge the decision)

39.13%

of advocates and campaigners told us they have experienced

Someone being prevented from leaving the place they live without alternatives set up to maintain mental and/or physical wellbeing

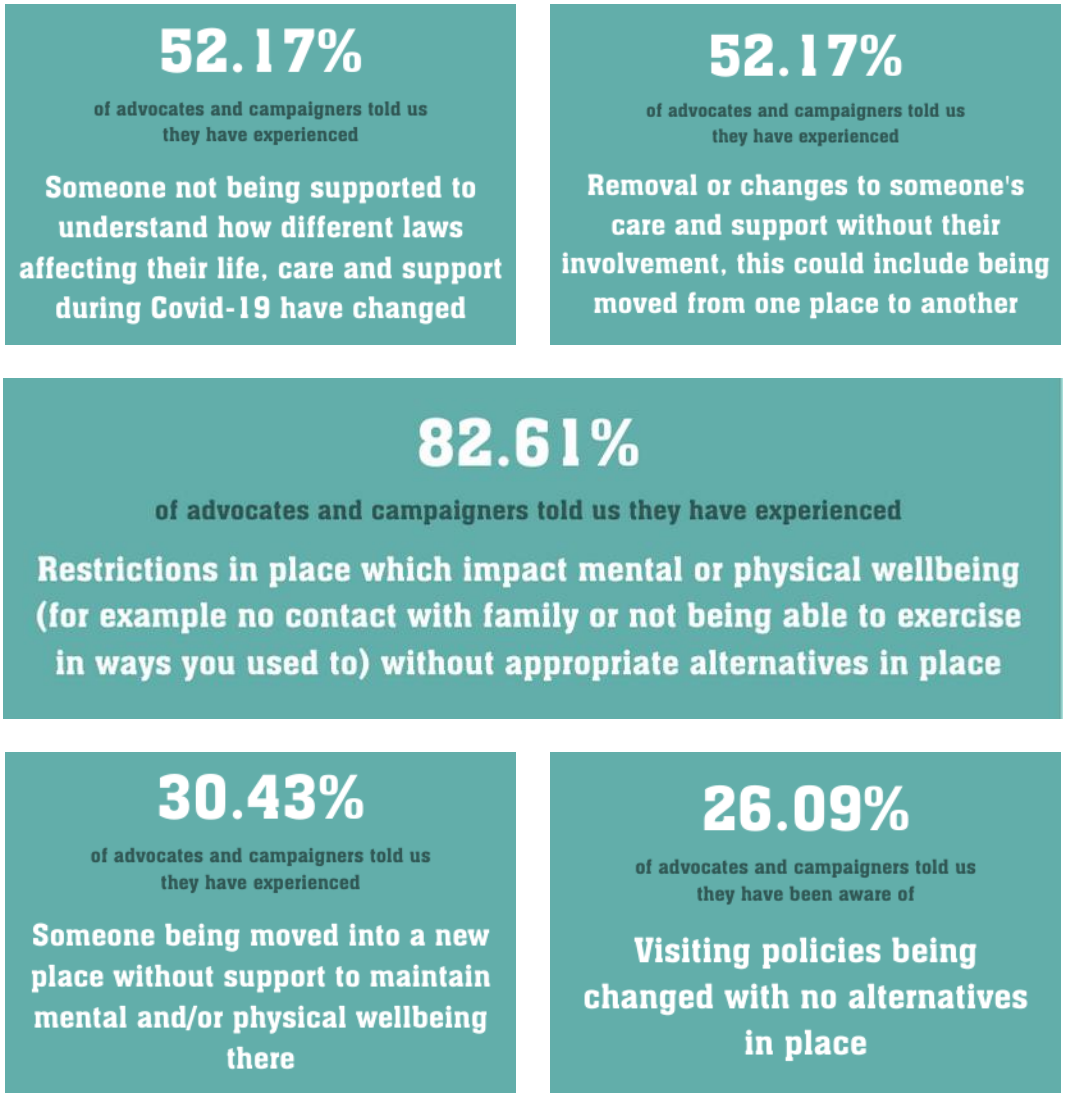
Right to a fair trial (Article 6 HRA)

34.78%

of advocates and campaigners told us they have experienced

Delays or cancellations to scheduled tribunal or court hearings to review care and support decisions

Right to respect for private & family life, home and correspondence (Article 8 HRA)

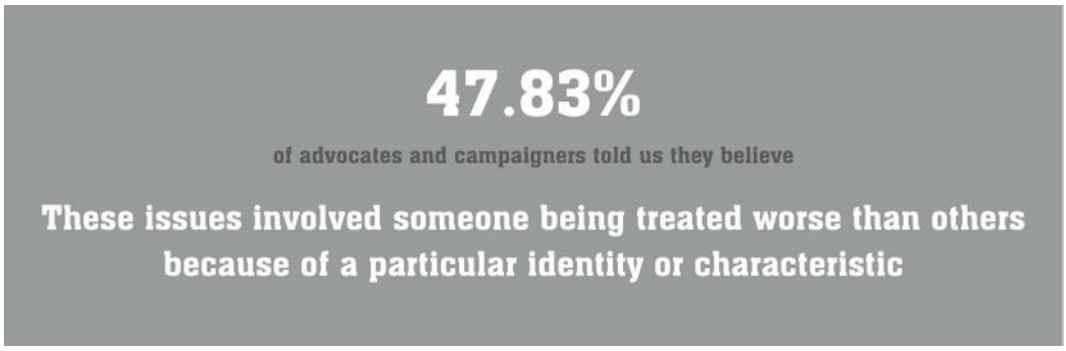


Freedom of thought, conscience & religion (Article 9 HRA)

Freedom of expression (Article 10 HRA)

Freedom of assembly and association (Article 11 HRA)

Right to non-discrimination (Article 14 HRA)*



*Article 14 is covered in more detail under non-discrimination above.

The right to education (Article 2, protocol 2 HRA)

Peaceful enjoyment of possessions (Article 1, protocol 1 HRA)

BIHR's recommendations on ensuring legality:

- Frontline staff must be supported to recognise and respond to a situation in which a person's legally protected human rights are at risk. In particular, risks to rights which can never be lawfully justified, such as being left in an inhuman or degrading situation. This is necessary during Covid-19 and beyond.

- Local leadership should have oversight of these human rights risks and use this to support non-discriminatory and proportionate service-level and strategic decisions in responding to the pandemic.

- Where the use of Emergency Powers has resulted in an unlawful restriction of rights, this should be independently investigated, using human rights as the central framework and remedies put in place.

- The Government must make it clear that as a Foundation Law, any other pieces of new legislation or guidance must be applied compatibly with human rights law. Furthermore, the Government must ensure public officials across the UK are fully trained, resourced and supported to meet these legal duties.

5. BIHR's Call to Action

At BIHR, we welcome the JCHR's call to evidence into the human rights implications of Covid-19. The procedural duty to investigate where human rights may have been risked, to remedy this and to put measures in place to prevent this from happening again is crucial. However, an inquiry which exists in isolation of immediate measures to ensure rights are respected and protected is not adequate. It cannot be the case that the UK operates on the assumption that there is an acceptable level of breaching human rights as long as this is reviewed afterwards.

People working in health and care (and in other public services) do not want to make human rights breaching decisions, they want to be given the tools, resources and support to uphold human rights in every single interaction with a person or their family, this is the case all the time but is even more crucial during Covid-19 when difficult decisions need to be made.

At BIHR, we know that the above information showing that, "76.92% of people working in health and care were not provided with legal training or clear information

about upholding human rights law" correlates directly with the figures showing the human rights issues during Covid-19.

The UK's approach to making human rights real for people in the UK needs to be grounded not in inquiries or reviews but in immediate actions now to ensure that rights are upheld in every interaction a person has with a public service (or those delivering a public function).

6. The voice of advocates

Finally, we asked advocates and campaigners, "Is there anything else you would like to tell us about human rights during Covid-19?"

"It feels difficult to think about this because there has been so little regard really for rights and this was because the strategy from the government ignored the value in the lives of the people we support from the start. How can you speak about a right to life when you discharge people with the virus into contained care environments and stop them accessing treatment (this might not even be through DNAR but just generally triaging decisions by paramedics or GPs that are made without formal oversight). It feels like rights are becoming meaningless and as advocates when you use a rights based argument you are met with a discussion about LA resources- this was before Covid-19. ...You challenge where possible, and instruct solicitors for cases with more to lose, where there are clear breaches or borderline decisions e.g. around capacity, but really there needs to be a shift in service delivery and more funding both for rights and eligible care needs before rights based arguments are effective. People who cannot understand the idea of having a right cannot fight for it, and advocacy caseloads/charities concerned with keeping contracts make it difficult to challenge, and relatives who understand rights arguments are thin on the ground."

Quotes from advocates and campaigners during Covid-19

"I believe the impact of the restrictions put on people who struggle to understand has been under-estimated and it has been unclear about exemptions to people with LD or mental health or dementia."

"Decision-making - no longer person centred. Myths around Coronavirus Act powers."

"Covid-19 has destroyed people's lives under this government's useless lockdown."

Quotes from advocates and campaigners during Covid-19

For more information about BIHR's support, resources and research on this issue please visit our Human Rights and Coronavirus Hub here.